

Perinatal palliative care: is palliative care really available to everyone?

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Submitted Jul 24, 2018. Accepted for publication Jul 27, 2018.

doi: 10.21037/apm.2018.07.09

View this article at: <http://dx.doi.org/10.21037/apm.2018.07.09>

In recent years, the diagnostic-therapeutic developments in fetal and neonatal medicine have profoundly changed the medical and ethical context in which pediatric healthcare professionals work.

The constant increasing survival of extreme premature neonates and newborns with life-limiting conditions, compels us to consider the quality of care provision and the quality of life of this ever-growing population (1,2).

At the Women's and Child's Department at the Padua University Hospital, we created a multidisciplinary working group to define a shared care pathway for newborns eligible for perinatal palliative care (PNPC). In 2016, during twelve meetings, involving all the staff working on the care pathway and the shared care protocol, the eligibility criteria, pre-/post-natal management procedures, and best practices for PNPC were defined. The aim was to offer PNPC to all eligible fetuses/infants/families and ensure the quality of the care provided.

At the end of 2017, we evaluated the efficacy and efficiency of our protocol: prenatal consultations by neonatologists for extreme preterm neonates or newborns with life-limiting conditions had increased (8 vs. 18/year). The number of newborns who died in the Neonatal Intensive Care Unit (NICU) was reduced by 30% (17 vs. 24), but, at the same time, the number of eligible newborns who actually received perinatal palliative care, was still limited (5 newborns of 24 eligible in 2016, 1 newborn of 17 eligible in 2017).

Despite a multidisciplinary care pathway, we had only partially implemented our protocol, consequently imposing a revision of our procedures.

PNPC is an emerging field within the pediatric palliative care sector that requires effective multidisciplinary cooperation. The multidisciplinary approach, involving all the members of the multidisciplinary team, must begin at the antenatal counseling for each eligible newborn. Prognostic inaccuracy and unpredicted survival potentially prevent the full implementation of the protocol. In the future, a consensus on an ethical framework for the decision-making process for these cases should be established. It is important to integrate palliative care into intensive care provision, to examine eligible newborn cases with the pediatric palliative care team, and teach NICU clinical teams to provide primary palliative care (3,4).

Not only shared protocols but also training and methodology are necessary to ensure PNPC delivery to every eligible fetus/newborn, thus making palliative care a realistic care option for everyone (5).

Acknowledgements

The authors would like to acknowledge Perinatal Palliative Care Workgroup of Padua's Hospital, Padua, Italy.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

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Cite this article as: Rusalen F, Cavicchiolo ME, Lago P, Salvadori S, Benini F. Perinatal palliative care: is palliative care really available to everyone? *Ann Palliat Med* 2018;7(4):487-488. doi: 10.21037/apm.2018.07.09